Comments to the Health Policy Oversight Committee – 12/18/2017 Submitted by Kay Marcel

UPDATE ON MY SON (Joel Marcel)

Joel has lost the only case manager he's known as a result of being assigned to United Healthcare (UHC). His case manager accepted another more stable employment opportunity versus possible employment with UHC.

Joel has not received any information from UHC about a case manager. He has received the UHC Member Handbook. He also received a Health Assessment Form that we did not complete because limited checklist options about disability and support needs were not relevant to someone with a developmental disability like my son and, therefore, will not provide meaningful information about his support needs.

TWO RECOMMENDATIONS

- 1. Advise DHS to immediately restore choice to the Medicaid program by:
 - 1) Allowing Medicaid recipients to remain with UHC or choose IME to manage and oversee their services; and
 - 2) Allowing the 2,000 people who had been served by Polk County Health Services prior to the departure of AmeriHealth Caritas to choose UHC, Polk County Health Services, or IME to manage and oversee their Medicaid services.

The current system DOES NOT provide choice and services necessary to ensure the health, safety and well-being of Medicaid recipients, in particular the most vulnerable long-term services and supports (LTSS) population.

Medicaid members currently have NO CHOICE in MCO provider and it is unclear when (or if) choice will be available.

lowans were told that managed care would result in a robust provider network, access to needed services, and improved outcomes. What has resulted is a decrease in the number of community providers, delays and loss of needed services, and poor quality of life outcomes.

Advise DHS to transition the Medicaid program and services back under the management and oversight of IME and begin with the most vulnerable LTSS population.

The current system is NOT conflict free. For-profit insurance companies manage patient care to reduce costs and maximize profit, which does not always align with the most beneficial plan of care for patients. This is especially true for the LTSS population whose care costs are among the most expensive due to the nature of their disabilities and their support needs often increase as they age even with preventive measures.

Medicaid members, especially those with life-long developmental disabilities, currently lack confidence that their service needs are assessed and approved by people who know them and whose only concern is identifying their support needs free of pressure and conflict from a for-profit employer.

Medicaid members also want and need confidence that the appeals process is swift and conflict-free if they disagree with an assessment or service plan.

PERSONAL CONCERNS

My husband and I are thankful that we are still able to provide the majority of support for our thirty-nine (39) year old son who still lives with us. Joel has a developmental disability and receives long-term support services through lowa's Intellectual Disability (ID) Medicaid Waiver. My husband and I will both turn 65 next year. We are increasingly aware that we will not always be able to support Joel as we do now. He will rely more and more on Medicaid long-term support services.

So I understand the need for a sustainable, cost-effective Medicaid program. We are trying to plan now for Joel to rely less on us and live more independently with appropriate supports that will ensure his health, well-being and safety in his own home where he can visit his family and friends who will advocate for him when his father and I no longer can.

No one desires sustainability in the Medicaid program more than those who must rely on it for LTSS. We recognize, though, that in addition to adequate funding sustainability means ready access to needed services.

In closing, I want to share with you my concerns that the administration continues to lack understanding of the unique and complex needs of my son and others with life-long disabilities, or recognize the problems that have resulted from the Medicaid managed care program. The Governor and DHS officials deny there are real and significant problems. They continue to promote the idea that Iowa's Medicaid program is "one of the best in the country" citing an on-line survey by J.D. Powers and Associates. The process and results of that survey are questionable especially when compared to the public comments heard at the DHS forum on December 5th and those you are hearing from constituents.

Also I share my concerns in an email to Secretary Foxhoven. His response included, "I am so sorry that some people have used this change to promote their own agendas to the detriment of our Medicaid members. By declaring that the program is failing and collapsing (something that is just not true), those critics do nothing more than create uncertainty and stress for the most vulnerable lowans."

The truth is the uncertainty and stress being experienced by individuals and families like mine is the result of losing services, providers, choice, and the ever changing information from DHS and the MCO's.

I greatly appreciate your service on this committee and the time you spend seeking input from individuals and families like mine. Your leadership is needed to do what is necessary to ensure a conflict-free, stable and sustainable Medicaid program that will meet the growing demand for long-term services and supports. I know there are advocates in lowa, including myself, willing to work with you and DHS officials to do so.

Finally, I want you to know that my son's birth and disability is NOT a tragedy. Joel has brought joy to our family and teaches us valuable lessons every day. His sense of humor brings daily laughter into our home. He is the kindest person I know; giving love unconditionally comes natural to him; he is quick to forgive and has the unique ability to not only forgive but forget hurts from others. Everyone who knows him is blessed by him.

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"Disability only becomes a tragedy when society fails to provide the things needed to live one's daily life." Judith Heumann